

HealthDesk for Hemophilia®: An Interactive Computer and Communications System for Chronic Illness Self-Management

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HealthDesk for Hemophilia is an interactive computer software application designed on the premise that successful chronic illness self-management requires information, self-care skills, on-going communication with health care providers, and user-friendly record keeping. The software was pilot tested for six months in the homes of eight hemophilia patients. The purpose of the pilot was to assess the impact of HealthDesk for Hemophilia on patient satisfaction, patient-provider communication, and user confidence in chronic illness self-management. Results from the pilot show that when HealthDesk for Hemophilia is made available to patients and their families, they use it, value it, and gain confidence in their illness self-management skills. Users also report high satisfaction with their health care providers.

INTRODUCTION

Health care organizations struggle with the constant challenge of offering high quality care while maintaining or reducing costs. At the same time, health-care consumers are demanding more information regarding their medical conditions and an increased role in their own care.¹ Chronic illness self-management software for patients and their families meets both these needs. HealthDesk for Hemophilia provides users with hemophilia self-management information and tools, while serving as a patient-provider communications link.

HEMOPHILIA TREATMENT AND SELF-CARE BACKGROUND

The World Federation of Hemophilia has put forth three fundamental goals of hemophilia treatment:

- To minimize disability and prolong life;
- To facilitate general social and physical well-being;
- To help each person with hemophilia achieve full potential while causing no harm.²

The major physical disability in hemophilia results from repeated bleeding into joints and muscles. This bleeding may induce inflammation of joint tissue and weakness and contraction in adjacent muscles. This

may lead to a self-perpetuating cycle of re-bleeding that eventually causes arthritic degeneration of the joint. Thus, efforts to prevent bleeding episodes and to treat bleeds promptly and thoroughly lead to long-term benefits. Supervised self-infusion programs at home can facilitate timely treatment. Success in such programs requires that patients and families:

- Receive thorough instruction in the recognition and treatment of bleeding episodes;
- Keep careful records of infusions;
- Cooperate with close supervision by a hemophilia treatment center, and visit the center for periodic evaluations.

In successful self-infusion programs, the patient's providers rely heavily on the patient's judgment about the presence of bleeding. Early symptoms of bleeding are most often recognized by patients before other observers detect any outward change. Therefore, hemophilia patients (and their families) must be partners in planning their own care. To be an active partner, however, requires that hemophilia patients and their families feel confident in managing the chronic condition. Access to information and tools for monitoring data and problem solving play a key role in helping patients and their families cope with the special demands of leading as normal a life as possible while at the same time managing a chronic condition such as hemophilia.

SOFTWARE DESCRIPTION

HealthDesk for Hemophilia is an interactive computer software application designed to provide home monitoring tools for hemophilia patients and their families. The software is programmed in Microsoft® Windows™. Users create a database of personal health records which can be sorted, stored, transmitted, and printed. The software also offers health education developed specifically for hemophilia patients and their families. The software is partitioned into three basic areas of functionality: the personal health records component, the health manager component, and the communications component.

Personal Health Records Component

There are fourteen core health records categories: background, lifestyle, personal conditions, family conditions, vaccinations, symptoms, drug allergies, health professionals, doctor visits, hospital visits, tests, medications, surgery, and finances. In addition there are two health records categories designed specifically for self-management of hemophilia.

Hemophilia Background. The hemophilia background category stores basic patient hemophilia history information such as type of hemophilia, level of severity, type of clotting factor replacement used, and the dose of factor used for most bleeding episodes. It also stores information on inhibitor response, and allergic reaction.

Infusions. The infusions category tracks self-infusion information such as date, time, specific site of bleed, factor product administered, lot number, units infused, reason infused, infusion number for bleed, and comments. There are also check boxes to note missed work or school days, hospitalization, and whether or not the infusion took place within the first three hours of the bleed. Documenting this information is important for facilitating discussion between patients and providers of long-term treatment planning.

Also, a pop-up dosage calculation window helps the user accurately calculate how many units of factor to infuse. The number of units of factor needed is based on the patient's weight and desired level of circulating factor. Users use the dosage calculation window as prescribed by their physician.

In addition, users can summarize their self-infusion information. This type of report is usually difficult for patients or providers to produce on their own. With this information patient and provider can better monitor infusions and factor use. Users can print records for themselves or, using the data upload feature, can send this information via modem to a central server where it is printed and filed in the patient's medical record. The information also helps assess problem joints that need monitoring to assure that pain and disability are reduced.

Communications Component

An upload feature provides communication between patients at home and their care providers. Using HealthDesk for Hemophilia and a modem, users send summary information of their infusion records, respond to standard questions, and place requests for prescription refills. Data can be uploaded

automatically when users log off the system or at other designated intervals.

Health Manager Component

There are five core health manager categories: exercise, weight management, stress management, heart health, and women's health. Education information is presented using hypertext, graphics, and animated illustrations. Users can choose what information they want to see and how much they wish to see at any given time. Information presented in this format facilitates comprehension and retention.³ Users can also track and graph personal health data of their own choosing, such as physical activity or medical test results. A resource guide provides access to national and local consumer health organization and newsletters.

Hemophilia Education Topics. Patient education topics includes inheritance of hemophilia, treatment of hemophilia, proper infusion methods, normal blood clotting, physiology of joint bleeds, importance of treating joint bleeds promptly, dental care, health insurance and financial concerns of chronic illness, and emergency guidelines for clinicians.⁴

Personal Data. Our sample categories for persons with hemophilia include hemoglobin, platelets, T4 cell count, and inhibitor/titer level (half-life of factor in range of 1-10). Actively tracking these categories helps patients monitor their current health status. In addition, viewing the data in graphical form increases patients awareness of health trends that may need further attention.

Resources. The resource guide is a directory of organizations of interest to persons with hemophilia. Each listing contains phone numbers, addresses, and a brief description. It is organized to allow the patient or family to access available information on a wide variety of support services. There is also a section in the resource guide for newsletters. National and state organizations and newsletters are currently listed. Local organizations may be added.

PILOT PROGRAM

A pilot implementation of HealthDesk for Hemophilia was conducted from February through July 1995 with patients living in New Mexico and Texas. The purpose of the pilot was to assess the impact of HealthDesk for Hemophilia on customer satisfaction, patient-provider communication, and user confidence in chronic illness self-management. In addition, we solicited user feedback on the

functionality, content, and usability of the software. We collected self-report data pertaining to the following variables: satisfaction, system usage, confidence in chronic illness self-management, emotional well-being, and behavioral intention regarding continued use of the system.

Procedure

Eight hemophilia patients and their families were recruited to pilot HealthDesk for Hemophilia in their homes for six months. All patients were males with severe hemophilia who self-infused at least three times per month. The age range was age 9 to age 39—three adults, four adolescents, and one child. The users of the software were adult and adolescent patients and parents of child patients. No prior computer experience was necessary. All participants were invited to a three-hour orientation session. Participating families were loaned a 486-PC with an internal modem for use during the pilot. A designated 486-PC server was installed at the coordinating home health care provider branch in Albuquerque, New Mexico. Data was collected in the following ways:

- Initial telephone interview;
- Post-intervention questionnaire;
- Uploading of all computer stored data to a designated provider server.

Results

Use of the Software. All but two families attended an orientation session. No one reported having difficulty setting up the computer at home. Half of the participants reported using HealthDesk for Hemophilia every day, 17% reported using it less than every day but more than once a week, and 33% reported using it once a week. When asked how they used HealthDesk for Hemophilia, all respondents reported using it to record infusions, 50% said they used it to browse for information, 50% said they used it to look up specific information, 83% said they had viewed existing records, and 33% said they recorded laboratory results received from their provider.

Software Usability. All respondents strongly agreed or agreed with the general statement, “I feel comfortable using HealthDesk for Hemophilia.” Participants used the infusion record screen more than any other feature of the software. All respondents strongly agreed or agreed with the following statements:

- “I like the way the infusions record screen is organized.”
- “I found entering data easy.”

- “The infusions record screen collects about the right amount of information.”
- “The infusions record screen is more convenient to use than pencil-and-paper records.”

When asked about the upload feature, 80% of the respondents strongly agreed or agreed with the statement, “I found the upload feature easy to use.”

Usefulness of the Software. On the whole, participants reported that the software was useful and an improvement over their previous method of self-monitoring. When responding to the question, “In general, how easy or difficult is it for you to keep a record of infusions and bleed sites?” 50% reported that prior to using HealthDesk for Hemophilia it was difficult or very difficult. While using the software, however, all respondents reported that it was very easy or easy. When responding to the question, “In general, how easy or difficult is it for you to keep track of the type of clotting factor, lot numbers, and number of units you use?” 66% reported that prior to using the software it was difficult or very difficult. While using the software, however, all respondents reported that it was very easy or easy. Prior to using HealthDesk for Hemophilia all respondents reported that it was difficult to “keep personal medical records for your own information or to share with your health care providers or insurance carrier.” While using the software, 83% reported that it was very easy or easy.

After using HealthDesk for Hemophilia in their homes for six months, all respondents strongly agreed or agreed with the following statements:

- “I like having access to HealthDesk for Hemophilia at home.”
- “HealthDesk for Hemophilia has made communicating with clinicians easier.”
- “I like using a computer to communicate with clinicians.”

In addition, 66% of respondents strongly agreed or agreed with these two statements:

- HealthDesk for Hemophilia has made me more confident that I can discuss health problems with my clinicians.”
- “HealthDesk for Hemophilia had made me more confident that I can make good hemophilia health care decisions.”

Future Use and Behavioral Intentions. After using HealthDesk for Hemophilia in their homes for six months, all respondents reported that, they were very likely or likely to browse health articles about hemophilia on their computer, and to forward self-infusion records to their health care providers via

their computer. Also, 80% reported they were very likely to communicate with other people coping with hemophilia and to order clotting factor and medications and supplies via their computer. In addition, 80% reported they were very likely or somewhat likely to read daily health bulletins pertaining to hemophilia on their computer.

Customer Satisfaction: All respondents reported high satisfaction with the services of the home health care provider that made HealthDesk for Hemophilia available to them. All reported that they would use services in the future and that they would recommend the services to others. When asked the question, "What is your overall satisfaction with the services," all respondents reported that they were very satisfied.

DISCUSSION

Despite the small sample size in this pilot, our users are likely representative of patients and their families who experience the day-to-day realities of living with severe hemophilia. All respondents were highly receptive to using computer software designed to help them with the routine tasks of chronic illness self-management.

Of special interest is the positive reaction of the adolescent members of the pilot group (12-17 years old). Parents of the adolescents reported that the introduction HealthDesk for Hemophilia into their homes encouraged the adolescents to assume greater responsibility for self-managing their hemophilia. Adolescence is usually a difficult time for individuals with chronic illness, as it is a time when they must assume primary responsibility for their health and well-being, while at the same time, cope with normal adolescent development factors such as demonstrating independence from parental control and seeking peer acceptance. The use of computers for illness self-management is a natural extension of electronic communication for this generation of users of the information superhighway.

HealthDesk for Hemophilia has the potential to benefit all members of the hemophilia community, including patients, families, physicians, home care providers, and third-party payers.

Benefits to Patients

Among the benefits to patients are easy record keeping, access to education and resources, improved communication with providers, and increased confidence in hemophilia self-management. Persons with hemophilia are encouraged to keep personal

health records. The desired records include dates and descriptions of bleeding episodes, hospital stays, reactions, and tests done. The records should also include the names of doctors and hospitals. These records are useful when giving a medical history.⁵ Our findings indicate that HealthDesk for Hemophilia facilitates this record keeping.

Persons with hemophilia and their families are also encouraged to understand all aspects of the disorder.⁶ It appears that HealthDesk for Hemophilia serves as a ready reference for patients, providing answers to questions in a self-paced learning environment. In addition, the resource guide enables patients to seek assistance from organizations committed to serving their needs. Computers can be an effective means of delivering education and support.^{7 8}

The ideal care and treatment model for hemophilia is comprehensive care. Comprehensive care is a team approach. The team is made up of experts in hemophilia related physical health and emotional health. Patients and their families are also important members of the comprehensive care team.⁹ As with any team, communication is the key to success. Communicating with care providers however, is often time consuming and frustrating for patients. Results from this pilot indicate that HealthDesk for Hemophilia may facilitate patients-provider communication by allowing patients to transmit infusion logs and other medical records information, to order additional medications and supplies, and to respond to standardized questions.

It is important to note that the benefits of communication and computer technology are not limited to those persons who are computer literate. An evaluation of the CHES interactive computer system with an underserved population showed that when computers were made available to new users the computer system was well received, extensively used, and produced feelings of acceptance, motivation, understanding and relief. The target population for this evaluation was a group of African American women with breast cancer. The women lived in impoverished neighborhoods in Chicago and had little or no previous computer experience.¹⁰

Benefits to Providers

Among the benefits to providers are increased consumer satisfaction, reduction of inappropriate utilization of services, and improved efficiency of care.^{11 12} Patients who keep better health records, who are better informed, who are can effectively

communicate with their providers, and who feel they are partners in their own care are more satisfied.

Research shows that health education and self-care information reduce unnecessary medical costs by decreasing unnecessary visits and encouraging necessary visits.^{13 14 15} This is most apparent when patients are partners in their own care. HealthDesk for Hemophilia optimizes patient-provider communication. Reduction of inappropriate utilization of services will also come about by improved monitoring of patient compliance through immediate transmittal of self-infusion data. It is a simple way to monitor patient self-care advice and adherence to prescribed self-care routines.^{16 17}

Our pilot results showed that HealthDesk for Hemophilia is a viable service option for hemophilia patients and their families. Results also showed that when HealthDesk for Hemophilia is made available, consumers use it, value it, and gain confidence in their illness self-management skills. In addition, users report high customer satisfaction.

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